

Lexia: Undergraduate Journal in Writing, Rhetoric & Technical Communication

Volume V

2016–2017

[How to Deal with Brain Death: Legal and Ethical
Considerations]

[Jessica Robinson]

James Madison University

Approximately 3,000 people are diagnosed as brain dead every year. This leads to about 3,000 families fighting to continue treatment, and 3,000 doctors trying to inform those families that their loved ones are gone and cannot come back to life. Brain death can be difficult to deal with because of the varying legal and ethical considerations that must be considered when diagnosing someone as brain dead. There is no distinction between what patients can and can't do, which makes it difficult for doctors to accurately do their job. Through researching the definition of death, the rights of a patient, and the ethical responsibilities of the doctor and the patient, I noticed a gap between the ethical responsibilities of the doctor and the impact the law has on how the doctor does their job.

Following a tonsillectomy in 2013, an eighth-grade girl, Jahi McMath, suffered rare complications which led to severe neurological damage. McMath was pronounced brain dead and doctors recommended the removal of ventilation. McMath's parents, however, did not believe their daughter was dead; she was breathing, her heart was beating, and her skin was warm and moist. They refused to let the doctors remove McMath from ventilation because they believed their daughter still had a chance at regaining consciousness. The doctors could not refuse her parents' wishes despite the fact that they knew that McMath would not regain consciousness, and unnecessarily keeping her alive would be wasting scarce hospital resources and the family's money on a dead body. In response to this unique scenario, Jessica du Tois and Franklin Miller (2016) explained that there must be an end goal if doctors are treating a person that has been pronounced dead. That goal can be organ donation or keeping a fetus alive, but it cannot be to bring the patient back to life. The case of Jahi McMath raised a question

about the distinction between brain death and cardiac death, and to answer it, legal and ethical considerations must be accounted for.

The Definition of Death

Death, according to philosophers, is an ambiguous term and is believed to mean different things. In a proposal written in 1981 to standardize the definition of death, three different definitions of death were discussed—whole brain death, higher brain death, and no brain death (Abram, Fox, Garcia-Palmieri, Graham, Jonsen, Krim, Medearis, 1981, p. 32). The whole brain concept of death refers to the complete loss of brain function, regardless of heart and lung function. This is the concept most people use when talking about “brain death.”

The higher brain concept of death refers to the loss of “personhood” or activities that make the patient human, like thinking, feeling, reasoning, and having human interactions. This concept of death is defined by the loss of what is essential to being a person and explains that a breathing body is not considered a person. This concept of death was questioned by Thomas (2012) who provided the counter example that people who are in a persistent vegetative state of partial arousal rather than awareness, and anencephalic babies who are born missing parts of their brain and skull, are not considered dead even though they have lost their ability for higher level brain functions. Thomas’s counterexample is effective because it is reasonable to believe that someone who has lost higher brain function still has the capability to live. This article brings into question the validity of defining death as a loss of higher brain functions because of cases like patients in a persistent vegetative state, where they are unable to clearly think, but they are still alive.

The final way to define death is the no brain concept of death where it is believed that cessation of metabolic functions defines death, not cessation of brain activity. In an article published in “The Monist,” a philosophical journal, philosopher Gary S. Rosenkrantz (2015) adds to the concept of no brain death by suggesting that when people permanently lose consciousness, they are not dead, but rather they are in a state of suspended animation. Suspended animation is defined as a stoppage of life without stopping the body’s metabolism, so the person is still alive. People who agree with this definition believe that the patient is still alive, regardless of their level of brain activity. This is a more religious concept of death and motivates families, like McMath’s, to want to continue treatment of the brain-dead patient. In the Bible, it states “For the life of the flesh is in the blood... for it is the blood that maketh an attonement of the soul” (KJV, Leviticus 17:11). This explains that the factor that determines a person alive is the ability for that person to function metabolically. Therefore, those who believe in Christianity, like McMath’s family, tend to believe that death is not defined by the brain activity of a person but rather by the blood flowing through their veins. Since there are many ways to define death, and all those ways are very different, it is difficult to qualify when someone could be considered brain dead. Abram et al (1981) called for a legal standardization of death, which eventually led to the adoption of the Uniform Determination of Death Act later in 1981.

Legal Aspects of Brain Death

Prior to 1981, there was no legal way to define death when the question of brain death was at hand. In response to Abram et al’s position in “Defining Death,” the United States government enacted the Uniform Determination of Death Act in 1981, which provided the government and medical professionals with a legal definition of

death. This act says that death is defined as either irreversible cessation of circulatory or respiratory functions or the irreversible cessation of the entire brain, including the brain stem (Uniform Law Commission, 2016). The Uniform Determination of Death Act standardized how death was viewed in the medical field and made it easier to classify who was dead and who was not. The act also allowed doctors and families of patients to know when treatment was no longer necessary.

Patients' Rights

Patients at a medical care facility have a certain number of rights that are guaranteed to them. Some of these rights include the right to informed consent, the right to accept or deny treatment, and the right to have a surrogate make decisions on the patient's behalf should the patient become unconscious. Two of these rights—the right to a surrogate decision maker and the right to accept or deny treatment—play a major role in how a doctor responds to a brain-dead patient.

The Right to a Surrogate Decision Maker.

Patients, when they become unable to speak for themselves, have the right to have a surrogate make decisions about their treatment on their behalf. When it comes to this decision-making process, sometimes surrogates and doctors make decisions that the patient would not have made. In an article written by Andrew Courtwright and Emily Rubin (2015), the accuracy of doctors and family members when deciding a treatment option for their loved one is brought into question. They explain that predicting patients' treatment preferences is difficult because patients are not there to give input and express their wishes. The article mentions a study that was completed in 1991, and another study that was completed in 2006. Both studies used the same procedure: they asked patients what their treatment preference was, and then asked

doctors in 1991 and family members in 2006 to decide upon a treatment plan based on a given scenario. The results of the study done in 1991 were that physicians could accurately predict the patient's care preference 50 to 70 percent of the time (Sekler, 1991). Similarly, in 2006, a study was done to expand on the results from 1991 to include family members of the patient. The study showed that family members and designated surrogates could accurately predict the patient's care preference 68 percent of the time (Shalowitz, 2006). Mentioning these studies strengthens Courtwright and Rubin's argument by providing two cases in which results of similar experiments showed the same thing—that surrogates and doctors alike were unable to accurately decide upon the treatment options the patient wanted. This also reveals a problem when caring for brain dead patients because if the surrogates and the doctors are inaccurate in their decision making, you cannot know for sure whether the patient would want to be kept on life support or taken off.

The Right to Accept or Deny Treatment.

When it comes to treatment options, patients can either accept or deny a treatment. Accepting treatment, or the right to treatment in general, means that patients have the right to receive proper and standard treatment in the care facility they are being held in. The right to deny or refuse treatment means that the patient has the right to decide whether they receive treatment, out of respect for their privacy and their body (Sederer, 2013). Sederer explains that problems could be caused in the medical field because patients and their families tend to abuse these rights. The journal article, *Legal and Ethical Responsibilities Following Brain Death: The McMath and Muñoz Case*, expands on these rights of patients and the problems they cause by explaining that not only are patients and families abusing these rights, but they are also remodeling

these rights so that they can demand treatment. The constant remodeling of patients' rights causes a problem because there is no law that prevents patients or their families from demanding treatment, and doctors must legally respect a patient's wishes (Gostin 2014). This article explains that the gray area between accepting and denying treatment allows patients and their families to command a doctor to administer treatment, even when that treatment option is not going to work. In cases such as brain death, this presents a problem because the patient is legally dead according to the Uniform Determination of Death Act. If the patient's family demands that their loved one continues treatment, the doctor must legally respect their wishes or face a lawsuit, because there is no legal distinction between when a patient's family is accepting treatment, or when they are demanding treatment.

Ethical Aspect of Brain Death

Along with legal aspects of brain death, there are also ethical responsibilities of both the patient's family or surrogate and the doctor. One ethical responsibility of the patient's family is to make sure the doctor is certain about the diagnosis of brain death. Patients and their families fear that standardizing the definition of death causes doctors to assume that the patient is dead and withdraw treatment without giving the patient a chance for recovery. However, the legal standards of death are so specific that a doctor can accurately diagnose death when proper tests are performed (Abram et al., 1981). This helps clarify the accuracy of diagnosis—when people are believed to be brain dead, many tests must be done to ensure that they really are dead. This improves Abram's point because it gives a counter example to the common belief that doctors withdraw treatment before giving the patient a chance to survive, showing that doctors do everything they can before pronouncing someone as brain dead. The doctors on the

other hand, have a different ethical responsibility—they are not to continue treatment on a dead body. If people have been correctly diagnosed as brain dead, it means they have permanently lost all of their brain function and will not be able to regain consciousness. In 1981, Abram, a member of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, explained that it is inappropriate to continue life-sustaining treatment on a dead body. To help his audience understand, he explains that although cardiac death, where death happens suddenly and the body cannot be brought back, and brain death, where the brain slowly loses function until it cannot be regained, may seem different in terms of how they happen, they are very much the same thing. In both scenarios, a vital bodily function is lost and cannot be saved. This comparison allows the argument to be more effective because it allows the audience to compare brain death to cardiac death, the latter of which clearly and without conflict defines death. In turn, the argument helps the audience understand that brain death is the same as cardiac death with little variation and should be treated the same way. Though this article is older, it is still relevant in the medical community and the idea has resurfaced since then. More recently, Lawrence Gostin (2014) commented on this subject by explaining that once people are declared dead, doctors are no longer required to give them treatment because treatment would be inappropriate for the scenario and would not bring them back to life. Family members of patients and doctors both have ethical responsibilities they must uphold, but since the law requires a doctor to fulfill a patient's, or their family's wishes, sometimes the doctor's ethical responsibilities must be sacrificed.

Conclusion

Overall, the legal rights of a patient trump the ethical responsibilities of the doctor, leading to misuse of hospital resources and unethical treatment of a dead body. After reviewing many different sources of legal and ethical responsibilities when faced with a situation such as brain death, there is a gray area when it comes to how death is defined and to a patient's right to treatment. The legal definition of death goes against other definitions of death, some of which are believed for religious reasons, and there needs to be a way to override the other definitions of death to properly care for patients. Addressing this murky area regarding the rights of patients would be beneficial because it would allow doctors to fulfill all aspects of their jobs correctly and would prevent patients and surrogates from interfering with the doctors' jobs, since the doctors were the ones who attended eight or more years of college to learn how to correctly treat patients. The right to treatment suggests that the patient must be provided with the best treatment option available for his condition, not that the patient or his surrogates can demand treatment when it is not an option. This puts doctors in a difficult position because if the patient is dead, they are ethically responsible to stop treatment; however, if the surrogates demand treatment for the brain-dead patient, doctors must legally fulfill their wishes or face a lawsuit if they do not. If surrogates keep demanding treatment for those who are legally dead, the doctor becomes unable to uphold his ethical responsibilities without breaking the law.

Lawyers and physicians must collaborate to change how death and patients' rights are defined to prevent patients and their families from abusing their rights and interfering with the doctors' jobs. The next step in closing this gap and making diagnosis easier for the doctor would be for doctors, lawyers, or even students in medical schools

to conduct multiple observational studies to determine how many people, when put in a situation where treatment options are very specific or not available, abuse the right to accept and deny treatment. Demanding treatments that were not offered to the patients would constitute abuse of this right. After analyzing the results of the study, redefining death and the rights of patients should be considered. Redefining death to close the gap between what is and what is not death, and to specify a patient's rights in a legal aspect will allow physicians to both legally and ethically fulfill their duties. Speaking as a student striving toward a career in medicine, I have sympathy for all the doctors and surgeons who have faced unnecessary lawsuits and problems due to the issue of the ambiguities in the definition of death and rights that patients have, and believe revising them will make the medical community a more reliable place to receive treatment.

References

- Abram, M. B., Fox, R. C., Garcia-Palmieri, M., Graham, F. K., Jonsen, A. R., Krim, M., Medearis, M. (1981) Defining Death. Washington, DC: President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.
- Courtwright, A. and Rubin, E. (2016), Who should Decide for the Unrepresented?. *Bioethics*, 30: 173–180. doi:10.1111/bioe.12185.
- du Toit, J. & Miller, F. (2016), The Ethics of Continued Life-Sustaining Treatment for those Diagnosed as Brain-dead. *Bioethics*, 30: 151–158. doi:10.1111/bioe.12178.
- Gostin LO. (2014) Legal and Ethical Responsibilities Following Brain Death: The McMath and Muñoz Cases. *JAMA*. 2014;311(9):903-904. doi:10.1001/jama.2014.660.
- Rosenkrantz, G. S. (2015). Life and Death. *Monist*, 98(3), 303. doi:10.1093/monist/onv011.
- Seckler AB, Meier DE, Mulvihill M, Cammer Paris BE. Substituted Judgment: How Accurate Are Proxy Predictions?. *Ann Intern Med*. 1991;115:92-98. doi: 10.7326/0003-4819-115-2-92.
- Sederer, L. I. (2013). The Right to Treatment and the Right to Refuse Treatment. Retrieved from: <http://careforyourmind.org/the-right-to-treatment-and-the-right-to-refuse-treatment/>.
- Shalowitz DI, Garrett-Mayer E, Wendler D. The Accuracy of Surrogate Decision Makers A Systematic Review. *Arch Intern Med*. 2006;166(5):493-497. doi:10.1001/archinte.166.5.493.

Thomas, A. G. (2012). Continuing the Definition of Death Debate: The Report of the President's Council on the Bioethics on Controversies in the Determination of Death. *Bioethics*, 26(2), 101-107. Retrieved from <http://eds.a.ebscohost.com/eds/pdfviewer/pdfviewer?sid=f9d80097-e52e-4171-af7bc8e2ac62a6ed%40sessionmgr4009&vid=0&hid=4210> .

Uniform Law Commission. (2016). Determination of Death Act Summary. Retrieved from: <http://www.uniformlaws.org/ActSummary.aspx?title=Determination%20of%20Death%20Act>.